

**NATIONAL INSTITUTE OF ARTHRITIS AND  
MUSCULOSKELETAL AND SKIN DISEASES  
INFORMATION CLEARINGHOUSE  
(NIAMS)**

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**MONTHLY PROGRESS REPORT**

**February 1, 2002 — February 28, 2002**

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**NATIONAL INSTITUTE OF ARTHRITIS  
AND MUSCULOSKELETAL AND SKIN DISEASES**

**NATIONAL INSTITUTES OF HEALTH**

*Contract Number N01-AR-8-2234*

**Submitted by:**

## National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse

February 1, 2002–February 28, 2002

NIAMS Information Clearinghouse staff responded to 1,910 public inquiries in February 2002, an increase of 6.3 percent from the number received in February 2001. (Please refer to *APPENDIX 1: Comparison of Requests Received* and *APPENDIX 3: Analysis of Requests Received and Responses Given*.) More than 10 percent of the requests were received via clearinghouse phone lines, slightly more than 19 percent were received via regular mail, 42 percent were received via e-mail, and more than 20 percent were received on the toll-free phone line. Patients made 62 percent of all requests. (Please refer to *APPENDIX 3: Analysis of Requests Received and Responses Given* and *APPENDIX 6: Requester Profile*.)

A total of 76,358 publications were ordered in February 2002, a slight decrease from the number ordered in February 2001, which was 78,591. NIAMS publications and information packages were provided to almost 78 percent of inquirers. (Please refer to *APPENDIX 2: Comparison of Publications Ordered* and *APPENDIX 3: Analysis of Requests Received and Responses Given*.)

The most requested single topic this month was arthritis in general, comprising 8.9 percent of all inquiries, followed by lupus at 7.3 percent, fibromyalgia at 5.8 percent, osteoarthritis at 4.2 percent, and rheumatoid arthritis at 4.1 percent. The majority of requests, more than 40 percent, concerned arthritis and rheumatic diseases. Slightly more than 22 percent of the requests concerned musculoskeletal disorders, 11 percent concerned skin diseases, and slightly more than 2 percent concerned sports injuries. (Please refer to *APPENDIX 8: Analysis of Requests by Disease Area*.)

The following report provides an accounting of the month's activities by contract task.

**National Institute of Arthritis and Musculoskeletal and Skin Diseases  
(NIAMS) Information Clearinghouse**

**List of Major Accomplishments: February 2002**

- ◆ Clearinghouse staff responded to the information needs of patients, families, researchers, and health care professionals by answering slightly more than 1,900 inquiries in February 2002. More than 76,300 clearinghouse publications were ordered in response to requests.
- ◆ The 10 publications with the largest volume distributed (followed by the number distributed) were as follows:
  - Do I Have Arthritis?/¿Tengo Artritis?* 20,755
  - Handout on Health: Osteoarthritis* 6,553
  - Handout on Health: Atopic Dermatitis* 5,718
  - Childhood Sports Injuries and Their Prevention* 2,980
  - The Many Shades of Lupus* 2,735
  - Handout on Health: Systemic Lupus Erythematosus* 1,915
  - Questions & Answers About Arthritis and Exercise* 1,820
  - Questions & Answers About Arthritis Pain* 1,772
  - Handout on Health: Rheumatoid Arthritis* 1,703
  - Questions & Answers About Fibromyalgia* 1,621
- ◆ The Alexandria (Virginia) Department of Recreation, Parks and Cultural Activities requested and was sent 1,000 copies of *Childhood Sports Injuries and Their Prevention: A Guide for Parents with Ideas for Kids*.
- ◆ YMCAs and YWCAs across the country continued to request copies of *Childhood Sports Injuries and Their Prevention: A Guide for Parents with Ideas for Kids*, as a result of the direct mailing sent to YMCAs and YWCAs in November. The response rate to the initial mailing has now surpassed 35%.
- ◆ The largest quantities of publications distributed this month included 20,000 copies of *Do I Have Arthritis?/¿Tengo Artritis?*, 5,000 copies of *Handout on Health: Osteoarthritis*, and 5,000 copies of *Handout on Health: Atopic Dermatitis*, which were sent to the Consumer Information Center in Pueblo, CO.
- ◆ Clearinghouse staff received and processed 389 calls on the toll-free line.
- ◆ Twelve NIAMS material packets were assembled and sent for the ARHP Advocacy Subcommittee Meeting.



## **TASK 1: MANAGEMENT AND PLANNING**

### *February Activities:*

#### ◆ **Reports:**

- The January 2002 NIAMS monthly progress report was submitted on February 20, 2002.
- The January 2002 NIAMS request tracking report was submitted on February 20, 2002.
- The January 2002 Eagle/NIAMS printing report was submitted on February 1, 2002.
- The Flash Publications status sheet was distributed at each NIAMS project meeting.

#### ◆ **Communications:**

- A project meeting was held on February 12, 2002.
- Internal clearinghouse staff meetings and publication tracking meetings were held weekly.

### *Next Steps:*

- ◆ Continue to refine the monthly project reports as requested by the NIAMS and as new aspects of the project develop.
- ◆ Continue to prepare and deliver the Flash Publications status sheet.
- ◆ Continue to provide special reports as requested.

## **TASK 2: INQUIRY AND MAILING SERVICES**

### *February Activities:*

#### ◆ **Inquiry Response:**

- *Staff Training:*
  - Online Health bulletins from Reuters, the Associated Press, and the *New York Times* appropriate to the NIAMS Information Clearinghouse were circulated daily.
  - Staff continued to screen NIAMS Information Clearinghouse and corporate library resources, including new reference arrivals.
  - Regular staff meetings were held.
  - A continuing education session on the NIAMS Website was presented to the staff.
- *Response to Public Inquiries:*
  - In the month of February, NIAMS Information Clearinghouse staff responded to a total of 1,910 inquiries. Of these inquiries, 19.1 percent (364 requests) were received through the U.S. Postal Service. Exactly 20.4 percent (389 requests) were received via the toll-free number, and 42.0 percent (803 requests) were

received via NIAMS e-mail. Exactly 10.6 percent of the inquiries (203 requests) came through the NIAMS Information Clearinghouse phone line. The response to most requests (52.2 percent) was to mail a publication or an information package. Attachments (custom searches and non-inventory materials) made up 7.6 percent of responses. (Please refer to *APPENDIX 3: Analysis of Requests Received and Responses Given.*)

- Both screening and response times for answering inquiries were mostly within the 1- to 2-minute range. (Please refer to *APPENDIX 4: Requests by Response Time* and *APPENDIX 5: Requests by Screening Time.*)
- The vast majority of requesters (62.0 percent) were patients. Health care professionals made up 17.7 percent of the requesters for this period. (Please refer to *APPENDIX 6: Requester Profile.*)
- Inquirers heard about the NIAMS Information Clearinghouse from a variety of sources, including directory listings (8.2 percent); media listings (19.8 percent); Federal agencies (7.1 percent); NIAMS/NIAMS Information Clearinghouse publications (10.6 percent); the Internet (39.6 percent); health care professionals (1.5 percent); and sources such as family members, other patients, or friends (1.5 percent). Exactly 1.4 percent of users were repeat callers. (Please refer to *APPENDIX 7: Referral Source Profile.*)
- Most requests involved arthritis and rheumatic diseases: general arthritis questions comprised 8.9 percent of the requests; fibromyalgia inquiries, 5.8 percent; lupus inquiries, 7.3 percent; osteoarthritis inquiries, 4.2 percent; rheumatoid arthritis inquiries, 4.1 percent; scleroderma inquiries, 1.8 percent; and Sjögren's syndrome inquiries, 1.7 percent of all requests. Exactly 11.0 percent of the requests concerned skin diseases. Requests for information about musculoskeletal disorders made up 22.5 percent of all inquiries. (Please refer to *APPENDIX 8: Analysis of Requests by Disease Area.*)
- The largest number of requests came from people in New York (131), followed by California (105), Maryland (105), Florida (91), and Texas (90). (Please refer to *APPENDIX 9: Summary of Requests Received by State, U.S. Territory, Canadian Province, or Other Country.*)
- *Standard Response Materials:*
  - No new or revised publications were added during the month of February.

♦ **Publication Storage, Receipt, and Distribution:**

- The clearinghouse distributed more than 75,200 publications to requesters in February.
- *Do I Have Arthritis?/¿Tengo Artritis?* (20,755) was the most distributed publication, followed by *Handout on Health: Osteoarthritis* (6,553), *Handout on Health: Atopic Dermatitis* (5,718), *Childhood Sports Injuries and Their Prevention* (2,980), and *The Many Shades of Lupus* (2,735).



- Bulk orders were distributed to more than 130 organizations, including the following:

Requester	Publication Provided	Quantity
89 <sup>th</sup> Medical Group	Arthritis Pain (AR-188QA)	25
	Arthritis Pain Large Print (AR-188L)	25
	Arthritis and Exercise (AR-103QA)	25
	Arthritis and Exercise Large Print (AR-103L)	25
	Arthritis and Rheumatic Diseases (AR-27QA)	25
	Arthritis and Rheumatic Diseases Large Print (AR-27L)	25
	Osteoarthritis (AR-73HH)	25
	Osteoarthritis Large Print (AR-73L)	25
	Rheumatoid Arthritis (AR-13HH)	25
	Rheumatoid Arthritis Large Print (AR-13L)	25
Alexandria Recreation Department	Childhood Sports Injuries and Their Prevention: A Guide for Parents with Ideas for Kids (AR-211)	1,000
Beloit Area Community Health Center	Arthritis Pain (AR-188QA)	25
	Arthritis and Exercise (AR-103QA)	25
	Atopic Dermatitis (AR-68HH)	25
	Do I Have Arthritis? (AR-209)	25
	Fibromyalgia (AR-91QA)	25
Boston Copley Marriott	Arthritis Pain (AR-188QA)	25
	Fibromyalgia (AR-91QA)	25
	Knee Problems (AR-187QA)	25
	Shoulder Problems (AR-190QA)	25
	Sprains and Strains (AR-192QA)	25
Capitol Consulting Corporation	Frequently Asked Questions About Osteoporosis (AR-222)	150
	The Many Shades of Lupus (AR-231)	150
Children's Hospital	Juvenile Rheumatoid Arthritis (AR-112QA)	25
D&E College	Acne (AR-80QA)	25
	Sprains and Strains (AR-192QA)	25
Family Community Fellowship C.O.G.I.C.	Arthritis and Exercise (AR-103QA)	100
	Avascular Necrosis (AR-150QA)	100
	Hip Replacement (AR-149QA)	100
	Juvenile Rheumatoid Arthritis (AR-112QA)	100
	Systemic Lupus Erythematosus (AR-96HH)	100

Requester	Publication Provided	Quantity
Gettysburg Internal Medicine Associates	Arthritis and Exercise Large print (AR-103L)	25
	Atopic Dermatitis Large print (AR-68L)	25
	Polymyalgia Rheumatica/Giant Cell Arteritis Large print (AR-74L)	25
	Spinal Stenosis Large print (AR-189L)	25
	Sprains and Strains Large print (AR-102L)	25
	Vitiligo Large print (AR-05L)	25
Lakeville Memorial High School	Growth Plate Injuries (AR-203QA)	25
	How to Find Medical Information (AR-30)	25
	Knee Problems (AR-187QA)	25
	Shoulder Problems (AR-190QA)	25
	Sprains and Strains (AR-192QA)	25
Montgomery College	How to Find Medical Information (AR-30)	25
	Sprains and Strains (AR-192QA)	25
Newton County Health Unit	Arthritis Pain (AR-188QA)	25
	Fibromyalgia (AR-91QA)	25
	How to Find Medical Information (AR-30)	25
	Osteoarthritis (AR-73HH)	25
Platte Valley Medical Clinic	Acne (AR-80QA)	25
	Atopic Dermatitis (AR-68HH)	25
	Gout (AR-99QA)	25
	Osteoarthritis (AR-73HH)	25
	Psoriasis (AR-97QA)	25
	Sprains and Strains (AR-192QA)	25
Rheumatology Consultants of East Tennessee P.C.	Fibromyalgia (AR-91QA)	25
	Gout (AR-99QA)	25
	Shoulder Problems (AR-190QA)	25
	Spinal Stenosis Large print (AR-189L)	25
Slauson Middle School	Childhood Sports Injuries and Their Prevention: A Guide for Parents with Ideas for Kids (AR-211)	550
	Scoliosis in Children and Adolescents (AR-131QA)	550
The Family Learning Place	Acne (AR-80QA)	25
	Childhood Sports Injuries and Their Prevention: A Guide for Parents with Ideas for Kids (AR-211)	25
	How to Find Medical Information (AR-30)	25



Requester	Publication Provided	Quantity
	Juvenile Rheumatoid Arthritis (AR-112QA)	25
	Scoliosis in Children and Adolescents (AR-112QA)	25
	Systemic Lupus Erythematosus (AR-68HH)	25
Womack Army Medical Center	Acne (AR-80QA)	25
	Atopic Dermatitis (AR-68HH)	25
	Psoriasis (AR-97QA)	25
	Rosacea (AR-181QA)	25
	Systemic Lupus Erythematosus (AR-96HH)	25
	Vitiligo (AR-05QA)	25

◆ **Data Collection, Tracking, and Reporting System:**

- Overall, the five most distributed publications were
  - *Do I Have Arthritis?/¿Tengo Artritis?* 20,755
  - *Handout on Health: Osteoarthritis* 6,553
  - *Handout on Health: Atopic Dermatitis* 5,718
  - *Childhood Sports Injuries and Their Prevention* 2,980
  - *The Many Shades of Lupus* 2,735

(Please refer to APPENDIX 10: Active Inventory, APPENDIX 11: Inactive Inventory, and APPENDIX 12: NIAMS Information Clearinghouse Publications Sent to the Consumer Information Center in Pueblo, CO.)

- Clearinghouse staff responded to 803 e-mails received through the clearinghouse e-mail address. (Please refer to APPENDIX 3: Analysis of Requests Received and Responses Given.)

*Next Steps:*

- ◆ Foster continued NIAMS/NIAMS Information Clearinghouse communication on any new developments/information/procedures for inquiry response.
- ◆ Continue to examine current reporting strategies for potential improvements.

**TASK 3: MATERIALS DEVELOPMENT**

*February Activities:*

- *Questions & Answers About Arthritis and Rheumatic Diseases:* All text revisions were approved and the printing package was delivered to the NIAMS.
- The Clearinghouse publications order form was updated, and copies were distributed to the staff.



- Clearinghouse staff completed substantial revisions to the last of the 25 information packages. Since November, the following have been sent to the NIAMS for review:
  - Alopecia Areata
  - Amyloidosis
  - Ankylosing Spondylitis
  - Arthritis and Diet
  - Arthritis in Children
  - Bunions
  - Bursitis/Tendonitis
  - Cartilage
  - Hair Loss in Women
  - Heel Pain
  - Itching
  - Keloids and Hypertrophic Scars
  - Knee Replacement
  - Lichen Planus
  - Low Back Pain
  - Neck and Cervical Spine Disorders
  - Osteomyelitis
  - Pemphigus and Other Blistering Disorders
  - Polymyositis/Dermatomyositis
  - Porphyria
  - Psoriatic Arthritis
  - Repetitive Stress Disorders
  - Scoliosis in Adults
  - Sun and Skin
  - Sweating Disorders

*Next Steps:*

- ◆ Continue to format publications as requested by the NIAMS.

#### **TASK 4: DATABASE DEVELOPMENT, MAINTENANCE, AND SEARCHES**

*February Activities:*

- ◆ **Maintenance of the CHID AR Subfile:**
  - 50 new records for the AR subfile were cataloged and abstracted for the April 2002 quarterly load.
  - The number of searches of the AR subfile has remained around 2,000 searches per month for the last 6 months, even though the trend in searches of the entire database has continued to increase. The AR subfile was the seventh most frequently searched individual subfile this month.

- *CHID Online* usage totaled 1,901 searches of the AR subfile out of a total of 224,532 searches done on the *CHID Online* Web site. The number of online searches of the AR subfile decreased almost 3 percent from January to February. The number of overall CHID searches was almost 7 percent more than in the previous month. (Please refer to *APPENDIX 13: CHID Online Usage Summary*.) The top five terms used by those searching the AR subfile were “arthritis,” “rheumatoid,” “lupus,” “skin,” and “fibromyalgia.” No NIAMS-related terms were among the top 20 terms searched in the entire CHID database.

♦ **Identification, Acquisition, and Screening:**

- Staff members continued to identify and acquire items for future loads by screening catalogs and other sources.
- Journal articles identified by clearinghouse staff were screened and copied for inclusion in future loads. Staff continued to read appropriate journals (as part of the continuing education program) and review them as candidate items for the CHID AR subfile.
- New issues of selected titles were circulated to NIAMS staff.

♦ **Establishing, Updating, and Maintaining Mailing Lists:**

- The ITIMS mailing lists were maintained, including requested additions, deletions, and changes.
- The following mailing labels were requested during this reporting period.

Date	Code(s)	Number of Labels
2-20-2002	16, 2, 5, 7, 12	806
<b>Total:</b>		<b>806</b>

*Next Steps:*

- ♦ Continue to prepare new records, modifications, and deletions for future loads of the CHID AR subfile.
- ♦ Continue to screen publishers’ catalogs and journal/newsletter articles for CHID (ongoing).
- ♦ Continue to maintain the onsite archive collection and catalog, along with CHID material, periodical, and reference book collections (ongoing).
- ♦ Continue to contact professional and voluntary organizations, especially members of the Coalition of Professional and Voluntary Organizations Concerned With the Programs of the NIAMS, for new and updated materials for CHID (ongoing).
- ♦ Continue to produce mailing lists as requested.
- ♦ Make revisions and upgrades to ITIMS as needed or requested.

## TASK 5: SUPPORT FOR INTERACTIVE INFORMATION SYSTEMS

### *February Activities:*

#### ♦ **Web Site Design, Development, and Maintenance:**

- *IRPartners Fall/Winter 2001:* The electronic publishing staff converted the publication into the new online format and placed it on the FTP site for review.
- *Publications Order Form:* The electronic publishing staff incorporated the edits received from the Institute and prepared to place the order form on the home page when the redesigned site goes live.

### *Next Steps:*

- ♦ Convert the revised documents to the new template for online publications.
- ♦ Convert documents to HTML for placement on the Web site as requested.

## TASK 6: COMMUNICATION RESEARCH AND EVALUATION

### *February Activities:*

- Clearinghouse and warehouse staff continued to insert evaluation comment forms and pre-addressed return envelopes into orders.
- Clearinghouse staff began including a tie-in evaluation form for e-mail requests. The tie, to a site maintained by the organization performing the evaluation, was attached to each electronic response by the Clearinghouse to e-mail requests. This follows the same basic procedure as that used on the NIAMS Web site.

### *Next Steps:*

- ♦ Continue to distribute the survey for the required time period.

## TASK 7: OUTREACH AND PROMOTION

### *February Activities:*

#### ♦ **Networking and Liaison:**

- Information on the *Many Shades of Lupus* was listed in *Dermatology World*, February 2002.
- The NIAMS Information Clearinghouse was listed as an information resource in the 2002 edition of the *Maryland Arthritis Resource Directory*.
- Current contact information for the clearinghouse was sent to the Dorland Healthcare Information Clearinghouse on Disability Information for their 2002-2003 edition of the *Case Management Resource Guide*.



◆ **Promotion Plans:**

- Childhood Sports Injuries
  - Two more YMCAs and YWCAs requested a total of 140 copies of *Childhood Sports Injuries and Their Prevention*. In addition, 1,000 copies were sent to the Alexandria (Virginia) Department of Recreation, Parks and Cultural Activities. By the end of February, clearinghouse staff had received 96 requests from the YMCA/YWCA mailing, with 12,811 copies of *Childhood Sports Injuries and Their Prevention* shipped so far.
- NIAMS URL
  - Changes were made to the URL references in clearinghouse and NIAMS materials as needed.
- Press Releases
  - Clearinghouse staff sent out 954 Scleroderma Research press release mailings within contract time specifications.

◆ **Exhibit Support:**

- Clearinghouse staff sent materials for the University of Maryland Multi-Ethnic Career Fair, and picked up returns.
- The clearinghouse received the items returned from the University of Maryland Multi-Ethnic Career Fair and completed an exhibit report. (Please refer to *APPENDIX 14: NIAMS/NIAMS Information Clearinghouse Exhibit Report*.)
- Clearinghouse staff sent materials for the Women's Heart Day in Washington, DC, and arranged for returning items.
- The clearinghouse received the items returned from the Women's Heart Day in Washington, DC, and completed an exhibit report. (Please refer to *APPENDIX 15: NIAMS/NIAMS Information Clearinghouse Exhibit Report*.)
- Clearinghouse staff sent materials for the Dermatology Nurses Association conference in New Orleans as well as arranged for furnishings, material handling, and staffing.
- The clearinghouse setup, staffed, and dismantled our booth at the Dermatology Nurses Association conference in New Orleans.
- The clearinghouse received the items returned from the Dermatology Nurses Association conference in New Orleans and completed an exhibit report. (Please refer to *APPENDIX 16: NIAMS/NIAMS Information Clearinghouse Exhibit Report*.)
- Clearinghouse staff sent materials for the Academy of Dermatology conference in New Orleans as well as arranged for furnishings, material handling, and staffing.
- The clearinghouse setup, staffed, and dismantled our booth at the Academy of Dermatology conference in New Orleans.

- The clearinghouse received the items returned from the Academy of Dermatology conference in New Orleans and completed an exhibit report. (Please refer to *APPENDIX 17: NIAMS/NIAMS Information Clearinghouse Exhibit Report*.)
- Clearinghouse staff continued to make arrangements for upcoming conferences in 2002 including securing booths, registering staff, ordering furnishings, arranging material handling, and planning, ordering, and shipping publications and displays.

*Next Steps:*

- ◆ Continue to implement a promotional campaign for the new NIAMS URL, including in-house listings, referrals, and approved material from the NIAMS.
- ◆ Develop an exhibit report following each exhibit conference.
- ◆ Continue ongoing planning and arrangements for this year's conferences and exhibits.

## **TASK 8: CONFERENCE SUPPORT**

*February Activities:*

- Clearinghouse staff copied the pictures of the Community Health Center staff onto a disk for the NIAMS.

*Next Steps:*

- ◆ Prepare handouts or signage as needed for future NIAMS events.

## **TASK 9: GRAPHIC DESIGN, PRODUCTION, AND REPRODUCTION SERVICES**

*February Activities:*

- Graphics staff prepared the following printing packages for the NIAMS to send for production:
  - *Handout on Health: Atopic Dermatitis*
  - *Handout on Health: Osteoarthritis*
  - *Questions & Answers About Arthritis and Rheumatic Diseases*
  - *The Many Shades of Lupus*
- Graphics staff sent the following large-print documents to the printer for reproduction:
  - *Questions & Answers About Fibromyalgia*
  - *Questions & Answers About Knee Problems*
  - *Questions & Answers About Spinal Stenosis*
  - *Questions & Answers About Sprains and Strains*
- Graphics staff continued to provide specs and cost estimates, as requested by the NIAMS, for printing and duplicating a variety of materials.

*Next Steps:*

- ◆ Provide the NIAMS with specs as necessary for new, revised, and reprinted publications.
- ◆ Continue to incorporate the revised Questions & Answers booklets into large-print format as needed.

**TASK 10: FACILITIES**

*February Activities:*

- ◆ All facilities are in place.

*Next Steps:*

- ◆ Maintain facilities.

**TASK 11: TRANSITION PLAN AND CONTRACT CLOSEOUT**

- ◆ No action is required at this time.